Here's the story we've been expecting from New Orleans:

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For Houma girl, Katrina's disruption a matter of life or death

By KIMBERLY SOLET
Senior Staff Writer

HOUMA -- Before Morgan Burroughs began taking an experimental drug to help manage her rare and deadly muscle disorder, the 9-year-old could not do the simplest tasks: wiggle her toes, scratch her nose, stay up for hours for a long movie and popcorn.

The fourth-grader's parents, Jim and Dee Dee, never said it out loud, but they knew they were losing their only daughter to Pompe, a rare and debilitating disease with fewer than 10,000 sufferers worldwide.

Morgan's parents saved the Broadmoor Elementary student from the brink of death, however, at the end of 2003 the young girl was accepted into a program at Tulane Medical Center that allowed her to receive a drug called Myozyme.

Still in experimental stage, the drug is believed to sharply improve survival in infants and children with an untreatable genetic disorder such as Pompe, whose victims rarely live past the age of 2.

Morgan has been traveling from her Houma home to New Orleans for bimonthly injections of the drug for nearly two years, and her progress has been such that she can now lift 1-pound weights, struggle her way through a pushup and muster almost enough strength to turn her body over.

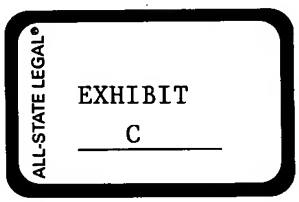
"It changed her life -- Morgan has a life now. Morgan was dying," said her mother. "We were losing her quickly. We were losing her to this disease."

As Hurricane Katrina flooded homes and sent thousands of residents packing, the storm also disrupted Morgan's twice-monthly enzyme-replacement therapy that her parents credit with her newfound lease on life.

Her father spent days trying to connect with doctors, friends, politicians -- anybody who could help his youngest child obtain her valuable medicine. Jim Burroughs said he traveled to Morgan City daily for access to a telephone to call the people his daughter needed to relieve her pain and suffering. A week's worth of round-the-clock pleas finally paid off last week in the one call that made a difference, to former Congressman Billy Tauzin.

Tauzin, now president of Pharmaceutical Research and Manufacturers of America, has long known of Morgan's disease, and family members say he was familiar with its effects: lax muscles, enlarged heart, crippled spine.

It took one phone call from Tauzin to the head of Genzyme, the company that makes drugs for rare diseases such as Pompe, to get Morgan her dose of the potent protein.



Today, Morgan and her mother are scheduled to fly to San Antonio to get the youngster's first infusion of Myozyme since Aug. 22, a week before the hurricane struck.

By the time the pair returns, family members hope the clinical drug trial will be shifted from Tulane to Terrebonne General Medical Center under the direction of Morgan's pediatrician since infancy, Ruthanne Gallagher.

"When I asked her, she never even hesitated," Jim Burroughs said.

Genzyme officials have approved the switch, and that's big news for a relatively small public hospital, as well as Gallagher and the Burroughs clan.

"No community hospital in the world is doing this," Jim Burroughs said. "Our doctor is taking on a big responsibility because this is a lot of work that your average physician probably wouldn't do."

Morgan is one of just 140 people in the world currently taking Myozyme in various trials and drug-availability programs, said Bo Piela, spokesman for Genzyme.

Patients participating are afflicted with severe Pompe disease, meaning they lack the enzyme necessary to break down sugars and convert food into energy. Pompe is a rare and debilitating disease, a deadly form of muscular dystrophy, affecting children and adults.

Children born with Pompe often die within two years because no medical treatment is available. Genzyme's drug, developed first in the Netherlands, uses the milk of genetically altered rabbits. The company filed for federal approval to administer the drug in July and expects a response from the U.S. Food and Drug Administration early next year.

Researchers have been looking at ways to treat Pompe disease for many years, and Genzyme started investigating and developing treatment in 1998. If approved, Myozyme would be the first treatment for the genetic ailment.

"We looked at several different products to do this," Piela said. "Myozyme looked most promising, and that's the one we applied for."

During their Texas stay, Morgan and her mother will meet Tiffany House for the first time, the first child in the world to ever take experimental enzyme-replacement drugs to battle Pompe disease. Tiffany is Morgan's hero, and just the thought of meeting the young woman profiled earlier this year in People Magazine makes the 9-year-old's freckled face glow.

Dee Dee Burroughs is equally excited about meeting Tiffany's mother, Marilyn, who moved the House family to Rotterdam, Holland, in the mid-90s so her then-teenage daughter could participate in a Dutch drug trial.

"We've been through so much together, all the pain and emotions and struggles. This trip is so important on so many levels," said Dee Dee Burroughs.

Although the drug still isn't approved, the impact of Morgan's enzyme-therapy

treatment is hard to overstate, said her physical therapist, Monique Trahan of Physical Therapy and Rehabilitation in Houma.

Trahan has been stretching Morgan's weak muscles, pushing the young girl to exhaustion with just a few repetitive arm extensions, since at least the age of 3.

When Morgan was a very young child, she could crawl and breathe on her own. But as her body grew, her muscles became incapable of supporting movement, and Morgan was hooked up to a ventilator and wheelchair and fed through a tube.

Before Myozyme, the little girl with the long wavy hair couldn't breathe or walk on her own. Eighteen months later, she can shake her shoulders, eat tiny pieces of junk food and wiggle her elbows like her favorite "Cheetah Girls" dancers.

When Morgan grows up, she wants to be a supermodel, and, in her mind, she has all the confidence in the world that someday the spotlight will follow her down the runway.

Bo Piela
Director, Corporate Communications
Genzyme Corporation
500 Kendall Street
Cambridge, MA 02142
Phone: 617 768 6579
Fax: 617 768 9682
E-mail: bo.piela@genzyme.com